# Sense of Self among Persons with Advanced Dementia

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Abstract: As humans, we have a sense of self, and at best, we are proud of our abilities and feel respected by other persons. Persons with dementia have been regarded losing their self. Quantitative research has shown that this is true, while qualitative research has shown that parts of self are severely affected while other parts remain even among persons with advanced dementia. These persons sometimes keep feeling "still the same" as before getting dementia. Their memory deficits help as does support from other persons. The theory of three aspects of self by the psychologists Rom Harré and Steven Sabat are presented, that is, the feeling that we are, who we are, and who we are together with other persons. Based on empirical research, suggestions will be given about how by promoting experiences of at-homeness, dignity, and being oneself related to others we can help persons with advanced dementia experience themselves as valuable persons.

Keywords: advanced dementia; anosognosia; confirmation; dignity; self

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#### INTRODUCTION

As human beings, we need to know that we are and who we are. We need to be proud of our abilities and feel respected by other persons. These experiences can often be hard to achieve for persons with dementia, partly due to symptoms of dementia and to a great extent due to other persons' reactions. There are reports that persons with dementia lose their self and also that it is at least partly preserved. A systematic review revealed that studies performed with quantitative methods generally described that among persons with dementia self was affected, while qualitative studies tended to find that self was at least partly preserved (1). These results are in line with Sabat (2) who argued that self should be investigated by sensitive methods.

The Latin root of the term dementia means to be out of one's mind (3), and dementia has been described as leading to affected persons losing their self and becoming non-persons (4). Thus, it seems reasonable that the term dementia has been subject to criticism, and the American Psychiatric Association has replaced it with the phrase "major neurocognitive disorder" in the Diagnostic and Statistical Manual (DSM-5) (5). Sabat (6) argues that we should not reduce persons to brains but see the persons behind the dysfunctional symptoms and remember our shared humanity. Those living with dementia are semiotic persons, that is, their behavior is driven by meaning, as they, for example, have the capacity to show shame and pride and to feel concern for other persons' well-being (7). They are also relational beings and their behavior is an effect of neuropathology, their reaction to these effects, others' ways of treating them and their reaction to that treatment (8). Healthy persons often use negative stereotyping of persons with dementia which may lead to these persons themselves using self-stereotyping (9).

There are several types of dementia diseases, with Alzheimer's disease as the most common type. The disease progresses from a mild stage, via a moderate stage, to an advanced stage in which affected persons are dependent on others in most situations (10). In the literature about care, the term "dementia" is sometimes used and sometimes the type of dementia is identified. Here, I use the term "dementia" when I refer to literature using the terms "Alzheimer's disease" or dementia without further specification.

## SYMPTOMS OF DEMENTIA

The cognitive symptoms of dementia can be described as four A's, namely amnesia (impaired memory), apraxia (impaired ability to organize sequences of movements in space), agnosia (impaired perception), and aphasia (impaired language ability) (11). Amnesia affects first the short-term memory and later also the long-term memory. A decreasing autobiographic memory (incident memory about specific personal events including context and personal semantic memory such as names of friends) affects sense of self (12). In interviews, persons with moderate dementia can often provide short accounts of their experiences. They may narrate fragments of their life story: childhood, education, family life and professional life. Several persons describe specific events such as leaving home to go to school (13, 14) and narrate thoughts about their future life, that is, about possible selves (15). Apraxia causes

problems with performing everyday tasks like, dressing, eating, grooming, and walking. Agnosia causes difficulties in recognizing, for example, colors, persons, objects, odors, shapes, and sounds. Aphasia leads to difficulties with both speaking and comprehending speech (16). Persons with dementia use circumlocutions and paraphrases as they forget words, and they need prolonged time to understand the meaning of what has been said, and to formulate answers (17). They also often can compensate by using extralinguistic means such as gestures and tone (18).

#### **SELFHOOD**

There is no consensus about the meaning of the concepts of identity, person, personhood, self, and selfhood. The terms are often used interchangeably although there are many different conceptualizations (19–20). Studies on the sense of self in persons with dementia have used various concepts or failed to describe the concepts used. Here, I use the term "self" also when I refer to authors who use the terms "identity" or "personhood". Thus, I use these terms as interchangeable.

The psychologists Sabat and Harré have together (21), separately (17, 22), and together with other researchers (23) published about a social constructionist theory of selfhood in persons with dementia.

The embodied, material human being they label "person," and the linguistic expressions we use to refer to ourselves they label "self." Selfhood is expressed both as speech and behavior in public discourse. Sabat and Harré describe self as tripartite: Self 1, Self 2 and Self 3. Self 1 (the self of personal identity) expresses our embodied experience of being singular continuous persons located in space, time and in a local moral order. We experience this aspect of selfhood in that each of us has one single point of view of the world, that is, our continuous experiences of events that form the narrative of our lives. Through the use of first-person singular pronouns, we take responsibility for our actions, feelings, and experiences as being our own and tell autobiographical stories. We manifest Self 1 when we speak in first-person indexicals ("I," "me," "mine," "my," "our") or indicate Self 1 nonverbally for example by pointing to ourselves (21, 24). Self 1 is a necessary condition to be able to reflect on our personal attributes (Self 2) and exhibit them in appropriate social situations (Self 3).

Self 2 is comprised of how we perceive our physical and mental attributes such as eye pigmentation, height and weight, educational achievements, political and religious convictions, sense of humor, and vocational pursuits. We have beliefs about our attributes, such as that they are adequate or outdated and also emotions related to them such as pride or disdain. Some Self 2 attributes have long histories such as being a daughter, while some may be more recent such as being diagnosed with dementia. Self 2 can be restricted and unrestricted. The restricted Self 2 is about how we perceive ourselves to be in the moment, while the unrestricted Self 2 includes both how we are in the present, how we were in the past and may develop in the future, that is, our relatively constant, temporary or ever-changing attributes, such as traits, skills, and our beliefs regarding these attributes. We manifest multiple Selves 2 (22).

As persons with advanced dementia usually remember past attributes better than recent ones, they may feel proud of already lost attributes (25). For persons

with dementia, new Self 2 attributes include deficits connected to the neuropathology of the disease (24) and results of their attempts to adapt to the disease (26).

Self 3 (social personae) is a complex concept, in that it includes the perspectives of both the displayer and the perceiver. It is the display of Selves 1 and 2 to other persons. How we display Self 3, depends on the situation, on how other persons position us and how we position ourselves to them through actions or inner dialogues (23, 27-28). Persons with dementia may lose their sense of selfworth and feel depersonalized, depressed, and angry when healthy persons behave in manners that can be classified as "malignant positioning" (28-30). Previous research has described both the negative positioning of persons with dementia (27) and the understanding and support that they sometimes receive (13). It is obvious that support from other persons is important for preserving a sense of self (20, 30). If others focus on dysfunctional Self 2 attributes of persons with dementia, their Self 3 (social persona) is restricted to "the patient" (28). If other persons focus on remaining healthy Self 2 attributes, it is possible for the afflicted persons to construct worthy Self 3 that makes them experience pride and satisfaction. (24). We manifest multiple Selves 3 that are constantly reconstructed in the interplay among persons (22).

Studies based on the Harré–Sabat theory of selfhood have shown that among persons with mild to moderate dementia, Self 1 was not affected during the course of dementia, whereas Selves 2 and 3 were (13–15). A few studies using that theory concern persons with advanced dementia (e.g., 24, 31–33). Studies that do not use the Harré–Sabat theory have found that some aspects of sense of self were preserved while other aspects were reduced among persons with advanced dementia (e.g., 34–37). Kontos (38) argued that selfhood is an embodied dimension of human existence persists even with advanced dementia. These persons have several preserved abilities despite losses of cognitive functions, for example being able to assess their own internal state of being such as feeling cold (39) and experiencing pain (40). Here, I use the term "advanced dementia" to describe information in articles about persons with moderate to advanced dementia as well as with advanced dementia.

#### PERSONS WITH ADVANCED DEMENTIA

Having advanced dementia involves many strains. Neighboring persons, carers, and everyone who meets these persons need to provide them support.

## Awareness and lucidity

Although persons with advanced dementia are often described as having lost their self (4), their sensory and perceptual awareness has been found retained (41). These persons show distinct individual reactions to particular kinds of stimuli, and they, for example, differentiate between pleasant and unpleasant experiences, or various pieces of music (42–44). If the self is lost, it is difficult to understand the meaning of *moments of lucidity* (cognitive fluctuations) that have been identified when persons with advanced dementia that seem "not there" suddenly show

that they understand, remember, and care (42, 45). It was evident that lucidity during conversations with a women with advanced dementia occurred when her communication partner supported her by showing that he shared her expressed view, repeating and reformulating her words, using positive words and statements, helping by suggesting words and starting, completing and ending sentences and not emphasizing errors in her speech (46).

## **Suffering**

Living with advanced dementia includes several negative experiences. When writing about *suffering* among persons with advanced dementia, several researchers write about experiences of pain and bodily distress (47). Few writers have explicitly focused on the other various experiences of suffering in persons with advanced dementia although carers often feel that these persons indeed suffer.

Eriksson (48) described three categories of suffering: "suffering of life" (for example grief due to the death of a friend, or feeling abandoned when friends do not pay visits to the nursing home), "suffering of illness" (effects of having dementia such as not feeling at home, having problems communicating), and "suffering of caring" (distress caused by received care). An example of "suffering of illness" is that several persons with advanced dementia have neuropsychiatric symptoms such as apathy, depression, irritability, agitation, sometimes delusions, hallucinations, and sleeping disorders (49). Examples of "suffering of care" are reports that carers have been observed treating persons with advanced dementia as object (50) which reasonably cause them suffering. Living with advanced dementia can also be experienced as a relative well-being (29) mainly through carers' compensating for problems related to the disease (51).

# Anosognosia

Many persons with advanced dementia have been reported to suffer from explicit or implicit "mnemonic anosognosia" anosognosia that makes them seem unaware of deficits caused by neurodegeneration although they may demonstrate implicit awareness (52–54). Their memory deficits can make their sense of self become a "petrified self," that is frozen in time and sometimes reflects the features that were accurate in early adulthood and perhaps even in childhood. Thus, memory impairments hinder the persons to update information about self. Sometimes, they may register impairment but they cannot integrate the information into a coherent picture of their situation. This may lead to stable but inaccurate evaluation of experiences and actions (54).

# Moments of homecoming

Feeling at home is a fundamental aspect of human existence (55), and it is important for our sense of self (56). Thus, losing one's home is losing one's self. To feel at home through the life cycle has been described as feeling related to oneself, significant activities, significant others, significant places, significant things, and to feeling a sense of transcendence (57). Persons with advanced dementia often appear to feel homeless, they may walk around, asking where they are and

searching for their home. They have problems feeling at home both in their former homes and in their new places of residence (58). The understanding of how important the experience of at-homeness is for our sense of self and well-being has led to an endeavor to create care environments where persons with advanced dementia can feel at home. However, although carers try to furnish the rooms as homely as possible it is often hard to document positive effect on the persons' daily life (59). Observation of nursing home residents with advanced dementia showed that they alternated between expressing feeling at home (at-homeness) and not feeling at home (homelessness) both verbally and nonverbally. They showed often short lived moments of homecoming that were characterized by "being released from burdens and demands (e.g., not being required to make choices), being united with actions (e.g., being helped to use previously familiar routines when getting dressed), and being reached by language (e.g., being spoken to with familiar words)" (60). One woman seemed to live and feel at home in two worlds simultaneously, that is, she interpreted some things that happened at present as something that happened earlier in her life (61). In her "rememberedworld," she took care of her small children and had coffee with her friends and expressed astonishment about the fact that some nice and friendly persons entered her room, made her bed and invited her to dinner. In her "care home-world," she could tell her carers about her grandchild having taken an exam.

#### Communication

Persons with advanced dementia may show some retained abilities to communicate, they for example sometimes are using politeness when communicating (62). Their communication difficulties are, however, more often acknowledged. They can show lack of interactional synchrony such as integrating verbal and nonverbal communicative cues to a whole and synchronize their actions with their communication partners by adequate turn-taking. First the carer talks, then the person answers, then the carer answers, then the person shifts theme etc. The lack of synchrony makes behavior chaotic and fragmented. The persons' sensitivity to representative meaning and less to affective meaning is reduced due to decreased arousal and attentiveness. They often send vague undifferentiated verbal and nonverbal cues that are difficult to interpret for the communication partner. They also show problems interpreting the communication partners' cues and they need prolonged time for responding to their partner. They may use short sentences but more often single words or even react with primitive reflexes (63). Communication partners sometimes have to impute or attribute meaning to the vague cues, that is, they make guesses that are based on their previous experiences with the person in question and with other similar persons or on empathy or intuition (50, 64). Sometimes, the communication can depend on the communication partners imitating each other (65). When I tried to help a person with advanced dementia to eat and the person did not seem to understand, I demonstrated what I meant by opening my own mouth, chewing and swallowing. I ate an air meal. Suddenly, the person seemed to understand and started eating (The author's experience). Both imputation of meaning to vague cues and imitation can help the persons feel like partners being answered, that is strengthening the Self 3.

At the end state, persons with advanced dementia may become mute (66). Hughes (67) argues that there are other means to understand persons with

dementia than understanding the words they use. It is about sharing a form of life, it is about understanding the context, and feeling what the persons express. This is like using affect attunement, that is, the carer tuning into the persons' affective state to be able to help them to reduce negative affect and increase positive affect (68, 69). In this way, communion between the partners is created. According to Stern (70), the sense of self starts with the parent and infant being in communion, that is, participating in and sharing emotions and vitality effects that, for example, are expressed through intensity and rhythm. Later, the sense of self gradually develops through interaction with others throughout one's history to also include cognitive dimensions. As their cognitive abilities decrease, persons with advanced dementia increasingly need to be in communion with carers to preserve their vulnerable self. Söderlund et al. (71) reported positive results from using the Feil's validation method during one-to-one conversations with persons with advanced dementia. The focus was not the facts about what was expressed but rather the feelings behind what the persons tried to talk about and the aim was to treat them as adults and increase their feelings of self-worth and well-being. Eggers et al. (72) described two somewhat different ways of interpreting the communicative cues of persons with advanced dementia, partly by establishing communion with them through affect attunement and partly by putting various fragments together until a picture of the meaning of utterances and behavior appeared. This was like completing a puzzle.

### **AGENCY AND COMMUNION**

Agency and communion have been described as fundamental modalities in human beings' lives (73). Communion is the urge to be connected and unified with others. The positive themes of communion are love/friendship, dialogue, caring/help, and unity/togetherness, whereas the negative themes are separation, rejection, disillusionment about people, and another's misfortune (74) Agency implies a quest for autonomy, self-realization, and separation from other people. The positive themes of agency are self-mastery, status/victory, achievement/ responsibility, and power/impact, and the negative themes are, failure/weakness, losing face, ignorance, and conflict (75). For a positive sense of self, we need agency (individuality) and communion (togetherness). Experiences of agency and communion have been assessed among persons with dementia (76). Although there are no clear-cut borders between the modalities, it seems as communion is more relevant for Self 1 and Self 3 and agency for Self 2.

## **Strengthening Self 1 communion**

Being treated and even feeling as a non-person reasonably means suffering. Therefore, it is important to help persons feel as *persons* with a sense of self. Research has shown that the Self 1 is preserved among persons with advanced dementia. Even when they almost entirely answer "yes" or "no" to questions, they still show that they can experience themselves as "I" (32, 60). Still it seems reasonable to suggest that we can help persons preserve their feeling of being an I by making them feel that they are seen and listened to, that is that they are. This kind

of behavior has often been labeled confirming actions and seems a type of communion.

The concept *confirmation* is based on Martin Buber's philosophy and is described by Cissna and Sieburg (77, p. 254–260) as the process through which we endorse others by showing them recognition, acknowledgement and acceptance of their self-definition. Thereby they get help forming and maintaining human relationship. Cissna and Sieburg emphasize that confirmation includes four key elements: (i) The element of existence (the individual sees self as existing). (ii) The element of relating (the individual sees self as being-in-relation with others). (iii) The element of significance, or worth. (iv) The element of validity of experience. Observations at a small group living for persons with advanced dementia revealed that staff confirmed persons by accepting the ways they spoke and acted by making them feel accepted and allowed to be just as they were. A person who thought the ward is a church was not corrected as long as he appeared to feel good. Another person who found it meaningful to carry things around was allowed to do that as long as no one else was disturbed (78). It seems reasonable that confirmation could be seen as strengthening persons' Self 1.

## Strengthening Self 2 agency

Experiences of using motoric and other abilities can be understood as part of agency. Because Self 2 concerns persons' perceptions of their abilities, it seems logical that there is a need that they both get opportunities to use their abilities and also get help to remember how they previously used their abilities. They most easily remember what happened during their childhood (54) and often express they are proud of these memories. In articles about needs of persons with advanced dementia, agency is mentioned (51, 78). To my knowledge, there are few studies presented about agency among persons with advanced dementia. There are, however, articles about topics that could be seen as agency. Together with their respective co-workers Kihlgren (79) and Ekman (80) analyzed video-tapes of morning care sessions with persons with advanced dementia and carers. The carers were taught about the Erikson (81) theory of eight stages of man and encouraged to, in a concrete way, promote the persons' experiences of trust, autonomy, initiative, industry, identity, intimacy, generativity, and integrity during morning care sessions. The comparison of behaviors and speech before and after the intervention showed that the persons with dementia displayed more and more ability (79) and that carers who spoke the persons' mother tongue (Finish) were most successful in helping them use their latent abilities than carers who only spoke Swedish (80).

Persons with advanced dementia may get help to recognize and remember important themes or episodes from their life history. As the ability to recognize is better preserved than the ability to recall, they might remember a phenomenon when reminded although they cannot recall it (17). They can have an unconscious or implicit memory of past experiences (38) and often remember emotions better than facts (81). As persons with dementia best remember their life before the debut of dementia and later their earliest memory, they most easily can express their experiences by referring to memories from their childhood (54). They may for example call their mother when they feel unsecure (82). When they perceive the emotions in a conversation, they can go back in memory to an experience with the same emotions to understand what the conversation is about (83).

Thus, when a person with advanced dementia asks a carer: You are my mother, aren't you, this does not have to mean that she thinks the carer really is her mother. Instead it might mean that the interaction with the carer made the person feel being loved and when she sought an experience with the same emotional tone from the past, she found memories of her mother.

At the last stages of life, persons with advanced dementia often experience eating difficulties, especially swallowing problems (84–85). By participant observations of meals Eggers (86) described fragmentation when the persons with advanced dementia did not seem to recognize what was going on, the persons involved, the things used, or recognize themselves in the meal situation. Carers counteracted fragmentation by showing attentive interest in the interaction, valuing the persons as human beings, considering the symptoms of the dementia, and striving for mutual interpretation of the meal situation.

## **Strengthening Self 3 communion**

Strengthening persons' Self 3 seem to mainly concern themes of communion. Self 3 has been found especially vulnerable when persons with dementia are negatively positioned and do not get support of others (17, 28). This means that actions that promote the wellbeing of these persons are strengthening their Self 3. Few articles about well-being concern persons with advanced dementia due to the fact that they cannot take part in studies that require answering complicated questions. They can, however, take part in easy conversations and become observed, thus in qualitative research (87). Kaufmann and Engel (51) included persons with advanced dementia in a study based on a Tom Kitwood's model of needs and described well-being according to the themes comfort (small pleasures of life providing relaxation, consolation); attachment (company with human beings, animals and objects, support); inclusion (being part of a community, feeling recognized); occupation (e.g., listening to the radio, exercise, participation in activities); identity (role maintenance, recognition, familiar rhythms and habits). Jetten et al. (12) reported that life satisfaction that was lower among persons with mild dementia than among persons with advanced dementia. Reasonably this could be related to anognosia among person with advanced dementia (54). There are several means to improve the sense of wellbeing among persons with advanced dementia such as using multisensory stimulation for example including music and massage (88), singing (89), dancing (90), animals (91) and dolls (92). Listening to well-known songs or music and to positive stories from their own lives can strengthen the feeling of being important. Music, touch, dance and rocking can mean comfort for persons with advanced dementia (43, 69). The stimulation of the senses can be combined with ordinary nursing actions. A review of 21 intervention studies on persons with advanced dementia, in which aromatherapy, music, simulated presence (for example, listening to a tape recording of their partner), touch and multisensory stimulation, have been used, showed no proven scientific evidence but carers' proven experience that the methods are effective, sometimes they fit, sometimes not (93).

As a positive Self 3 means that the persons with advanced dementia feel proud of themselves, loved and acknowledged other persons' acts toward them are of utmost importance, actions that promote the persons feeling dignified certainly would strengthen self 3. Manthorpe et al. (94) described *dignity* as a phenomenon involving an inherent self-respect and feelings of worthiness, and being respectfully recognized

and confirmed by others. Nordenfelt (95) wrote about four variants of dignity: Menschenwurde (human dignity), which is overall other variants of dignity, that is as it is part of being human it is the same for all people; dignity as merit (e.g., being a leader), dignity as moral stature (e.g., being an altruistic person) and dignity of identity (concerns self-image, self-respect, worth and value ascribed by oneself or others). Persons' dignity of identity can change over time, for example depending on if the persons are afflicted by dementia and how they are treated of others, which can result in physical, psychological, or emotional change or harm. Dignity of identity is connected to sense of self, and it is threatened if the persons have forgotten who they are.

The dignity as moral stature is about our moral actions. We can show that we know about their previous good properties and actions as persons with advanced dementia cannot upgrade their identity (54). Persons with advanced dementia should be cared so they can keep their experiences of human dignity , dignity as merit, dignity as moral stature and dignity of identity. When persons with advanced dementia are seen as having lost their self (4), their human dignity is questioned and there is a risk that they become treated as objects.

## SPIRITUAL AND CONSOLING CARE AT THE END OF LIFE

There is so far, no cure for AD. Within approximately 4 to 8 years, dementia usually leads to *dying and death*, although some persons live up to 20 years after being diagnosed (96). Persons may *die with dementia* due to various causes (97) or *due to dementia* as it is a lethal disease (98).

There are few reports about needs during end of life among persons with advanced dementia. A review of 10 articles published 1993–2013 mentioned physical, social, psychological, spiritual, supportive, environmental needs and needs related to individuality. The authors emphasized that as persons with advanced dementia have severe communication difficulties, we need more research about views of stakeholders (99). Analyses of focus-group discussions at four nursing homes showed that dying was silent and silenced, emotions were put into the background and death was talked about after a person's death. The staff did not talk about death neither with each other nor with the residents (100). This seems unfortunate as several residents have revealed that they were aware of the fact that they soon would die. One person emphasized that she was waiting to go to her real heavenly home. Another resident said that she was only living at the ward temporarily until she would meet her deceased spouse again and another one said that she wanted to listen to gospels while dying. Some did not speak about death and dying but reasoned about their funeral (60). At the last stages of life persons with advanced dementia often experience eating difficulties, especially swallowing problems (84–85). Several qualitative studies have reported that persons with advanced dementia at the end of life often exhibit aversive refuse-like eating behavior (101). There have been discussions about whether tube-feeding or comfort feeding should be used (102–103). The American Geriatrics Society (96) has recommended comfort feeding.

Spirituality has been regarded as "an integral, even fundamental, element of what it is to be a human being" (93, p. 765) and if we regard persons with advanced dementia as human beings it follows that they have spiritual needs. Spirituality among persons with advanced dementia has not, however, been

extensively studied. A literature review of scientific articles about spirituality did not report any study about persons with dementia (104) and another review study found expressed spiritual needs in 2 out of 10 articles (99). According to Kverno (93) there is a diversity of definitions of *spirituality* such as being connected to meaning-making. Spirituality should be understood as involving the dimensions of time and/or social space and stresses it's longitudinal, habitual dimension, that is, "the values, meaning and practices most deeply ingrained at the heart of 'who we are' are those which have been repeated and reinforced over and over again from our infancy" (p.773) and held together with other persons. Perkins et al. (105) reported that even persons with advanced dementia were able to engage in *spiritual practices* that provide life meaning in accordance with their values. Observations in a nursing home showed that some persons expressed a need for religious expression or participating in religious rituals (106).

Thinking about or even experiencing that one interacts with deceased dear loved ones can provide satisfaction (60). This finding seems to represent a tendency to gerotranscendence (107) and can be understood as related to the fact that among persons with advanced dementia memory for past events is better preserved than memory of recent events (12). Swinton (108) argued that spiritual practices can be beneficial for Christian persons with advanced dementia. When their memory fails their bodily memory can be reclaimed. He referred to Bergson's writing about a memory synonymous with recollection that represents particular things that have happened in the past and inscribes the past in the present (54). Swinton emphasized that we are embedded in our memories even when we cannot recall them, we are our memories. Persons with other religions or life views of course also need spiritual care adopted to their needs. Nursing home residents with moderate dementia expressed that religion is consolation for them (109). Persons with advanced dementia need consoling care (69, 110). The most important ingredient in consolation for these persons certainly is communion (69, 111) and it may provide them a feeling of being at home (112). However, it is most probable that they can get some moments of homecoming (60).

## **CONCLUSION**

Persons with dementia lose parts of their self which can be noticed when considering symptoms such as amnesia, agnosia, aphasia, and apraxia. Their own sense of self can be preserved during the entire course of dementia partly due to the fact that their amnesia makes it difficult for them to upgrade their life story. Of utmost importance is that other persons understand that persons with advanced dementia still are persons and support them to feel valuable.

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